

## **How nurses can support a child during blood cancer/lymphatic cancer treatment?** literature review

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<p>Abstract</p> <p>Children with blood and lymphatic cancer have been focus of research in many countries and it has widely been discussed of being the most common cancer type with children. Children goes through lot of behavioral changes, psychological health and physical appearance. Several different approaches have been proven useful to help children improve their coping and mental health status.</p> <p>The purpose of this study was to produce evidence-based information of the supporting methods that can be used with children who are phasing cancer treatment. The aim was to provide information by synthesizing existing materials about support that nurse can give to the child during cancer treatments.</p> <p>The study was carried out as literature review and analyzed with Inductive content analysis. The literature search was limited to child- and/or early stage of adolescent hood patients with the blood and/or lymphatic cancer, and who were going through cancer treatment, and were supported on during the care. The 8 articles that were used on the data were selected from CINAHL database and manual search. The limitation of the time was that the articles had to be published between 2005 and 2019.</p> <p>The study showed that nurse can help children with cancer treatment by managing the pain, creating safe environment, using Emotion- and cognitive-oriented strategies of coping, supporting child's parents and including them to the care, securing the self-determination right and providing enough activities to do. For example, talking to the patient and addressing their fears while taking their mind off from the scary things at the treatment. More specified research should be done on supporting child during cancer treatment.</p>		
<p>Keywords/tags</p> <p>Support, paediatric cancer, psychological support, Family-Centred Care, paediatric mental health</p>		
Miscellaneous		

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# 1 Introduction

About 40% of all the childhood cancer cases are concerning the area of blood cancers, (Leukaemia & Lymphoma Society, 2020). This literature review takes a deeper look into the subject, how nurses can support the child during cancer treatment.

Acute lymphoblastic leukaemia (ALL) is the most common cancer among children, adolescents and young adults, people who are younger than 20 years old. From 2010 to 2014, under 20 years old, children diagnosed with leukaemia is 26.4 percent of all the types of cancer among children in the US. (Leukaemia & Lymphoma Society, 2018).

Children go through emotionally and physically hard time while they are in treatment of blood cancer. Pain, fatigue, bone and joint pain are some of the symptoms which children have in Acute Lymphoblastic Leukaemia and Acute Myeloid Leukaemia (AML). These are very challenging symptoms to go through, thus the need of the support from the nurses is important. (Ghanbari, Pouy. 2018). What a child can handle emotionally depends on their intellectual and emotional development, hence the parents of the child are paying an important role during treatment and support. Fear of separation or not fully understanding the diagnosis, the challenge of giving right kind of support, is in the hands of nurses and parents, (Leukemia Foundation, 2018).

The aim of this study is to synthesise the existing material on how nurses can help children with blood-/lymphatic cancer during their treatment. The purpose is to provide the information to help and improve nursing care for children who are on cancer treatment. The research question: how can nurses support children during blood cancer/lymphatic cancer treatment?

## 2 Blood Cancer: Definition, Treatment and Interventions

### 2.1 Definition of Blood Cancer

WHO defines cancer as a large group of diseases which is characterized with abnormal growth of cells beyond cell groups usual boundaries, (WHO, 2018). In blood cancer, such as leukaemia, lymphoma and myeloma, the cancerous cells are affecting the bone marrow. In bone marrow, stem cells mature and develop blood cells into 3 different groups: red blood cells (RBC, erythrocyte), white blood cells (WBC), also known as leukocytes, and platelets (thrombocytes). With blood cancer this normal process is being interrupted, in which uncontrolled growth of abnormal blood cells is present; blood cells are not able to perform normally, many of its functions are being inhibited; higher amount of infections and bleedings, (American Society of Hematology, 2018).

#### **Leukaemia, Lymphoma and Multiple Myeloma**

**Acute Leukaemia** occurs in bone marrow and affects the stem cells where the precursor of the leukocytes has mutated cancerous. In leukaemia there is not one tumour like in many other forms of cancer, cancerous cells in leukaemia can be in the blood and/or in the bone marrow, (Salonen, 2015). Acute leukaemia has two main categories: myeloid- and lymphoblastic acute leukaemia. Acute leukaemia is forming quickly, and it can occur with people of all ages. (Salonen, 2015). Symptoms in Acute leukaemia are tiredness, fatigue, unintentional weight loss, fever or chills, pain in the bones, bleeding, difficult infections, shallow breathing, swelling, vomiting, rashes and gum problems, (Lohi et.al. 2013).

**Chronic leukaemia** is a slowly progressing condition where patient can be asymptomatic for a long time. In some cases, blood specimen is needed to be taken to see whether there is leukaemia or not. Like with acute leukaemia there is two main categories: lymphoblastic and myeloid. Chronic leukaemia

is usually suspected through blood tests. Symptoms including such as enlarged lymph nodes around your neck, armpit or in groin, tiredness, sweating and unintentional weight loss. (Salonen, 2015).

**Lymphoma** is a cancer in the lymphatic system, which plays a role in the immune system. Lymphatic system includes lymph nodes, spleen, bone marrow and thymus gland. There are many types of lymphoma existing, but the most common subtypes are Hodgkin's lymphoma (HL) and Non-Hodgkin's lymphoma (NHL). Symptoms such as swollen lymph nodes, persistent fatigue and fever can appear. (Friedman, Baisley 2012, 42-44).

## 2.2 Treatment methods

Cancers can be treated in different ways. The method is decided depending on the type of the cancer. With all the methods that are being used in cancer treatments, the purpose is the same; cancer improves, recurrence is prevented, cancer and disease is brought under control and the symptoms, which are caused by the tumor are alleviated, (Cancer Society of Finland, 2018). Blood cancers can be treated with chemotherapy, radiotherapy, stem cell transplantation and CAR T-cell therapy, (Leukaemia & Lymphoma Society, 2020).

The most common of all treatment methods with blood cancer is the chemotherapy and it is used for all ages. It includes strong cytostatic treatments which destroy the mutated cells, (MayoClinic, 2018). Stem cell transplantation is treatment where mutated stem cells are being killed with chemotherapy and new stems are being given from a healthy donor. This is being used for people under 55 years. It is a common way to treat blood cancer with children, (Lohi et.al. 2013). Radiation therapy is treatment which includes high energy radiation, ionizing radiation. Radiation therapy is given to a child when blood

cancer is localized. It is wanted to be given to support the effect of chemotherapy. When the effect of standard or intense chemotherapy is poor, radiation therapy can be used, (Canadian Cancer Society, 2018). CAR T-cell therapy is a relatively new way to treat cancer, which is used only in few countries including Canada and United States. In this therapy mode human T-cells are being modified to detected mutated cells, thus it can eliminate those cells that are mutated. It is shown to have greater response to blood cancer rather than other cancer types. (Filley et.al. 2018).

### **Treatments used with children**

**Chemotherapy** is the most common treatment method used with childhood leukaemia, and both HL and NHL, (WebMD, 2018, Friedman & Baisley, 2012, 42-44). Red blood cells (RBC), platelets and white blood cells (WBC) are formed in the stem cells which are present in bone marrow, cord blood and peripheral blood. Chemotherapy is a treatment where drug that is being administered contains powerful chemicals, which are killing fast-growing cells. The purpose of the treatment is to kill unlocated cancerous cells in the body, (MayoClinic, 2018).

Anti-cancer drug can be given Intravenous (I.v., to the vein), Intramuscular (I.m., to the muscle), as a pill, perorally (P.o., through mouth) or into the cerebrospinal fluid (CSF). Anti-cancer drugs are given usually as a combination and the treatment goes with cycles. Each treatment period is followed by a resting period to allow the body to rest and recover. (Canadian Cancer Society, 2018)

Symptoms are usually present in chemotherapy. The symptoms that one might experience during chemotherapy treatment include hair loss, nausea, vomiting, diarrhoea, loss of appetite, fatigue, fever, mouth sores, pain, easy bruising (from low platelet count) and constipation. (Reisi-Dehkordi et.al.



2014, 334) Possible side-effect of the treatment is Tumour lysis syndrome, which is a condition where killed cancer cells break down and release its contents to the bloodstream. Consequently, when this occurs in large amounts it can be stressful to the kidneys. The kidneys' job is to remove the substances, but with small children this process happens slower than with adults. This can cause accumulation, which kidneys are not able to remove at once. This accumulation can be prevented by giving enough fluids during the treatment. (American Cancer Society, 2018)

**Stem cell transplantation**, also called bone marrow transplantation, is a procedure where unhealthy blood-forming cells are being replaced with healthy cells. RBC and WBC are formed in the stem cells, which are present in the bone marrow, cord blood and peripheral blood. The patient receives chemotherapy and possibly radiotherapy. This is followed with stem cell transplant; stem cells from the donor are infused to the patient's blood, which travels to the bone marrow of the patient. The donor is usually a sibling or close relative, if they are a right match. If a close relative is not available, then unrelated person with the same tissue type can be the donor. Then new stem cells start to produce new healthy WBC, RBC and platelets. (Leukemia and Lymphoma Society, 2018) (Lohi et.al. 2013)

### **Radiotherapy**

When it comes to cancer treatment, radiotherapy is a commonly used treatment method, second most used type of treatment with children. Due to the different varieties of blood cancers, this is an effective method for treating localised blood cancer. Radiotherapy uses ionising radiation, which has high energy levels, radioactivity. In radioactivity the atom emits energetic particles/waves (radiation). Radiation breakdown the cancer cell and shrinks tumours by damaging the structure of the dividing cancerous cell. Almost half

of the cancer cases receive radiotherapy at some stage of the patient's treatment. Radiotherapy can be given directly towards the metastasis, tumour or can be given to wide area as well. (Cancer Society of Finland, 2018)

There are several ways to give radiotherapy; external- and internal radiotherapy. External radiotherapy is given by machine, meanwhile in the internal radiotherapy, the radioactive source is introduced into the body. Radioisotope- and radiopharmaceutical therapy are part of internal radiotherapy. When it comes to blood cancer treatment combining radio- and chemotherapy, it is most effective to give them both at the same time. This is called chemoradiotherapy. Radiotherapy is painless. (Leukemia and Lymphoma Society, 2018) (Lohi et.al. 2013) The side effects of the radiotherapy vary from the amount of dose, duration and the area where the treatment was given. (Cancer Society of Finland, 2018)

### **CAR T-Cell Therapy**

CAR T-Cell therapy, Chimeric Antigen Receptor T-cell therapy, is a relatively new method of treating cancer. It was founded by Gideon Gross and Zelig Eshhar at the Institute of Weizmann, Israel. The first design was done in 1987, but the first drug that was approved by U.S. Food and Drug Administration (FDA) on August 30, 2017. (CancerWorld, 2018)

CAR T-Cell therapy uses patients' own T-cells, which can be modified to detect and target any receptor. When it comes to blood cancer treatment, receptors of these T-cells are being modified to detect CD19, which lay on B-cell malignancies. It has been used for leukaemia treatment with relapsed or refractory B-cell ALL. (Filley et.al. 2018) (Lee, et.al., 2019)

Cancers treated with CAR T-cell method have several side-effects, whereas the Cytokine Release Syndrome (CRS) is one of the most common, and often needed to be treated afterwards. This is also one of the most common reasons

for hospitalization after successful treatment of cancer with CAR T-cell therapy. (Smith & Vanella, 2017, 29-31)

### **3 Impact of Cancer and Treatment on Parents and Patients**

#### **3.1 Blood Cancer Care Impact to Parents**

When a child of a family is diagnosed with cancer it is a stressful situation for the parents. Peek & Melnyk (2010, 306,311) bring up in their article that childhood cancer involves the whole family. Parents have reported it to be a scary and horrifying moment. Diagnosis caught parents by surprise. This shock causes parents to react strongly to the situation and it can harm parents' overall mental health, in which condition they might feel anxious, depressed and/or acquire post-traumatic stress disorder, PTSD. It has been reported that parents whose child has been diagnosed with cancer are more worried than the child. Mental health of the parents is necessary to take into consideration, when it comes to the care phase of the treatment. Parents are playing a big role in supporting the child; hence, it is good to take care of the mental health and worries of the parents. (Peek & Melnyk, 2010, 306,311)

When parents are worried the child feels also worried, hence, it is necessary to calm them if needed to provide better results to support the child. Thus, the parents have much stress upon them, confusion, aggressive behaviour, blaming others and self-blaming are very common as a first crisis reaction. These types of crises should be taken into account by the health care professionals. (Peek & Melnyk, 2010, 306, 311)

Post-traumatic stress symptoms (PTSS) can be seen in adults whose children are going through cancer treatment. The acute phase of the treatment has been reported to be the most stressful situation for parents. (Tremolada et al. 2012, 1448-1451) Parents who had better connection with the Team, which is part of the treatment of the child, have lower stress levels. Highest stress level point is

around six months from the diagnosis, the level remains about the same for the first year after the diagnosis. Emotionally parents go through a lot, thus, psychological symptoms of the parents are very common. (Tremolada et al. 2012, 1448-1449) Parents are affected by the stressful situations such as fear of remission and death. Confusion is experienced within parents when a child faces hospitalization. During in-hospital time, parents have the most stressful time. Parents are in high risk of developing burnout while their school age child are going through cancer treatment (Beheshtipour et.al, 2016, 91). It is undeniable that health care professionals should be taking care of the parents of the patients during stressful times. Parents are in risk of developing even higher stress levels than when they are suffering from the disease themselves (Beheshtipour et.al, 2016, 91).

Having increased amount of stress, after the diagnosis, and while they are in the hospital with the child, these factors increase the risk of burnout within parents. Burnout has a negative impact to the effect of help, which parents can offer. (Beheshtipour et.al, 2016, 95)

### **3.2 Effect of Cancer and the Treatment to the Children**

When it comes to cancer, just hearing the word can have profound impact on a person. Regarding the age of a child, this can be seen differently with children. Problems such as attention defect, memory- and language problems, depression, anxiety, fear, nausea, fatigue, vomiting, weakness, hair loss, limb function decrease can be taking place during and after the diagnosis and therapy. Childhood cancer is highly stressful for the child and the whole family. Due to the fast progression of the cancers with children, the treatment is more intensive compared to adults and the toleration towards the treatment is higher with children than adults, hence the side-effects can be more severe. (Scientific American, 2018) (Reisi-Dehkordi et.al. 2014, 334).

## Physical Effects

Great amount of studies has shown that within the children with cancer, side-effects occur in longer term, as well as stress reaction proceeds long after the conclusion of cancer treatment (Peek & Melnyk, 2010). Research by Krawczuk-Rybak, Panasiuk et.al. (2018) which was published by European Journal of Pediatrics, shows that there are many different side-effects present when a child is going through the treatment and late effects. The study focuses on the acute and late effects of cancer treatment and the health status of adolescents who have gone through childhood cancer. Their qualitative studies show that from 1761 adolescents who took part of the survey, 207 of them had normal function of all organs and 792 were having problems with four or more organs. (Krawczuk-Rybak, Panasiuk et.al. 2018, 440) The most numerous groups of people in the study was children with ALL. Over 25% of patients who presented with symptoms 38,8% had cardiac problems, 26,4% had digestive system problems, 31,1% of the patients had immunological problems, difficulties with chewing and/or dental problems were present with 28,5% of the patients, male gonadal dysfunction 26,3%, skin problems were present in 44,8% in the group of ALL patients in this done research. Children who were treated for AML had neurological (26,4%) problems present, respiratory (26,4%) problems and growth (34,0%) problems, female gonadal (38,5%) problems, which was not so much seen with children with ALL. (Krawczuk-Rybak, Panasiuk et.al. 2018, 440-442)

According to the research done by Krawczuk-Rybak, Panasiuk et.al. (2018, 440-441), children who have cancer, and are on anticancer medication treatment, have had problems with urinary tract problems (28.5%), skin problems (43.5%), dental problems and difficulties with chewing (26.6%), which causes trouble with young children with eating, hence, they do not want to eat because of the pain. Thus, the pain medication plays a big role while being on the

anticancer drug therapy. Skeletal muscle problems (23.5%), gastrointestinal problems (23.7%), immunologic disturbances (23.8%), gonadal dysfunction (male 25.7%) and endocrine problems (15.0% females and 21.0% males) can also occur. This study shows that the variety of effects of anticancer treatment on children were with higher frequency than with adults. As the children are individuals they react in a different way to situations. Children who had cancer treatment seemed to feel more insecure due to the physical changes that have happened to them. (Krawczuk-Rybak, Panasiuk et.al. 2018, 440-442, 444-445)

### **Emotional Effect**

Young children reflect the emotions from their parents. This is a natural way for a child to learn the emotions, and this reflection is playing a big role in the early stage of life. When a child has a cancer diagnosed and the treatment is going on, parents are usually stressed and worried, this can be seen from the child as well. Children are reading the expressions from the faces of the parents. If the parents are worried, the normal response for a child is to also be worried, and when the parents are stressed, it affects the child's social, emotional and behavioral adjustment to the diagnosis and to the treatment. (Peek & Melnyk, 2010, 306, 311) (Saarni, 2011, 6)

Children are likely not to understand the reason why there are many needles causing them pain during treatment. Hence, it is important for nurses to pay attention to explain why these things are done and to try to reduce the pain caused by the needles. As mentioned, the cognitive development level determines how well a child can understand the reason of the illness and pain. A toddler might not understand but only that something is not right, a child who is at school age might understand that they are ill and need treatment of some kind, and high school aged children understand well and are able to

search reliable information from the internet and get understanding from there. (Marcus, 2012)

Children have emotional burden due to the idea of not being at home, whereas at home they felt less ill. The behavioural changes are common with children who are going through blood cancer treatment. Children are being exposed to painful procedures, which can cause some traumatic memories to the children, which affects their mental health. Children in most cases feel sadness and confusion, due to this, children might act aggressively at times. Also, loss of freedom is reported to have emotional and psychological effects on children. (dos Santos, de Lima Costa et.al. 2017, 1617)

### **Psychological and Developmental Effects**

Marcus, 2012, says that children who have cancer have acquired multiple psychosocial issues. These children require special approach to conceptualize and operationalize the issues they are facing. Children might not understand the reason why they feel bad or ill. How children will understand the illness and reason why they feel as bad as they do, depend on the cognitive development level (Marcus 2012).

Health care professionals are not always able to meet these psychological needs of child patients. Children with psychological and physical experiences, who are going through cancer treatments, should be able to address their challenges properly, and this should be understood by health care professionals (Wiener, et.al. 2015, 1–18). It is reported that if psychological needs cannot be reached, it is at high risk that negative effects of cancer, such as depression, decreased pain tolerance, disability, post-traumatic stress disorder (PTSD) and fear of death, among other symptoms, will be in increase (McCaffrey, 2006, 59–66) (Marcus, 2012). Challenges related to the diagnosis and treatment, children, in most cases, experience stressful physical and emotional challenges

that could remarkably affect their well-being including physical incapacity, poor self-esteem, and educational progress can suffer (Wiener, et.al. 2015, 1 – 18).

Nevertheless, cancer treatment is not only affecting to the function of the organs, emotional and psychological health, but also to the development of the child as well. Long-term negative effects that cancer care and cancer itself can be affecting to the development of the brain with children (Scientific American, 2018). Change of environment can change the rhythm of the development of child. Children who are being hospitalized can phase challenges in development that house environment ensure. (dos Santos, de Lima Costa et.al. 2017, 1617)

## **4 Aim, Purpose and Research Question**

The aim of this study is to synthesise the existing material on how nurses can help children with blood-/lymphatic cancer during their treatment. The purpose is to provide the information to help and improve nursing care for children who are on cancer treatment. The research question is: how can nurses support children during blood cancer/lymphatic cancer treatment?

## **5 Research Methodology**

### **5.1 Literature Review**

A literature review is a mixture and analysis of studies that have a certain topic where the research has been based on (Rew 2011; Aveyard 2010, 5-6). Literature review has several types, the main idea of literature review is to



summarize the, already done, theoretical researches or empirical researches. This is to provide more encompassing understanding about the problem or the phenomenon. (Whittemore & Knafl, 2005) Literature reviews are informing about researches which are chosen to be built around a specific question that is also known as the research question. The aim of this research is to research how nurses can help children during their blood cancer treatment by finding data that has been made by others and analysing and applying the data together. (Whittemore & Knafl 2005)

The meaning of a literature review is gathering the published and unpublished data. (Aveyard, 2010) In this literature review, parts of systematic literature review methods are being used to get as reliable research results as possible. Systematic literature review is a review which uses specific questions that are being identified, in which categorical method and system are used to clarify, evaluate and appoint pertinent research. Meta-analysis or statistical methods can be used to summarize the results from different studies that are being used (Rew, 2011).

In literature review, four methods are used; forming the research question, planning the research, showing and discussing of results (Aveyard 2010). The main method chosen for this thesis is literature review. The study was done in county settings of one, but researches and information has been used from many countries.

## **5.2 Literature Search**

The articles that were used in the thesis were received from two main databases CINAHL (Ebsco) and manual search. 12 articles were discovered by manual search, 7 of those articles were in use. The articles were chosen using inclusion and exclusion criteria (shown in table 1) that was predetermined.

Table 1. Inclusion criteria for research articles

Inclusion Criteria	Exclusion Criteria
Answers to the research question and topic	Publications that were concerning other than paediatrics
Language of the publication is English or Finnish	Publications that are literature reviews
Scientific publication and Evidence-based materials	
Access to full text (for JAMK students)	
Studies that concerns the challenges that children and parents go through	
Studies have been published in 2005 or later	
Publication is relevant to subject	

Several combinations of keywords were tried before data was searched. The keywords used to search relevant articles were the following: **Child** (all phrasings included) AND **blood cancer** OR **leukemia** OR **ALL** OR **lymphoma** AND **treatment** AND **support** (all phrasings included) OR **effect**. Synonyms that were used for the word support, were **help** and **aid**. Only scientific research articles and evidence-based materials, written either in Finnish or English, conducted from 2005 until year 2019, were searched. Detailed search process of the articles is shown in Figure 1.

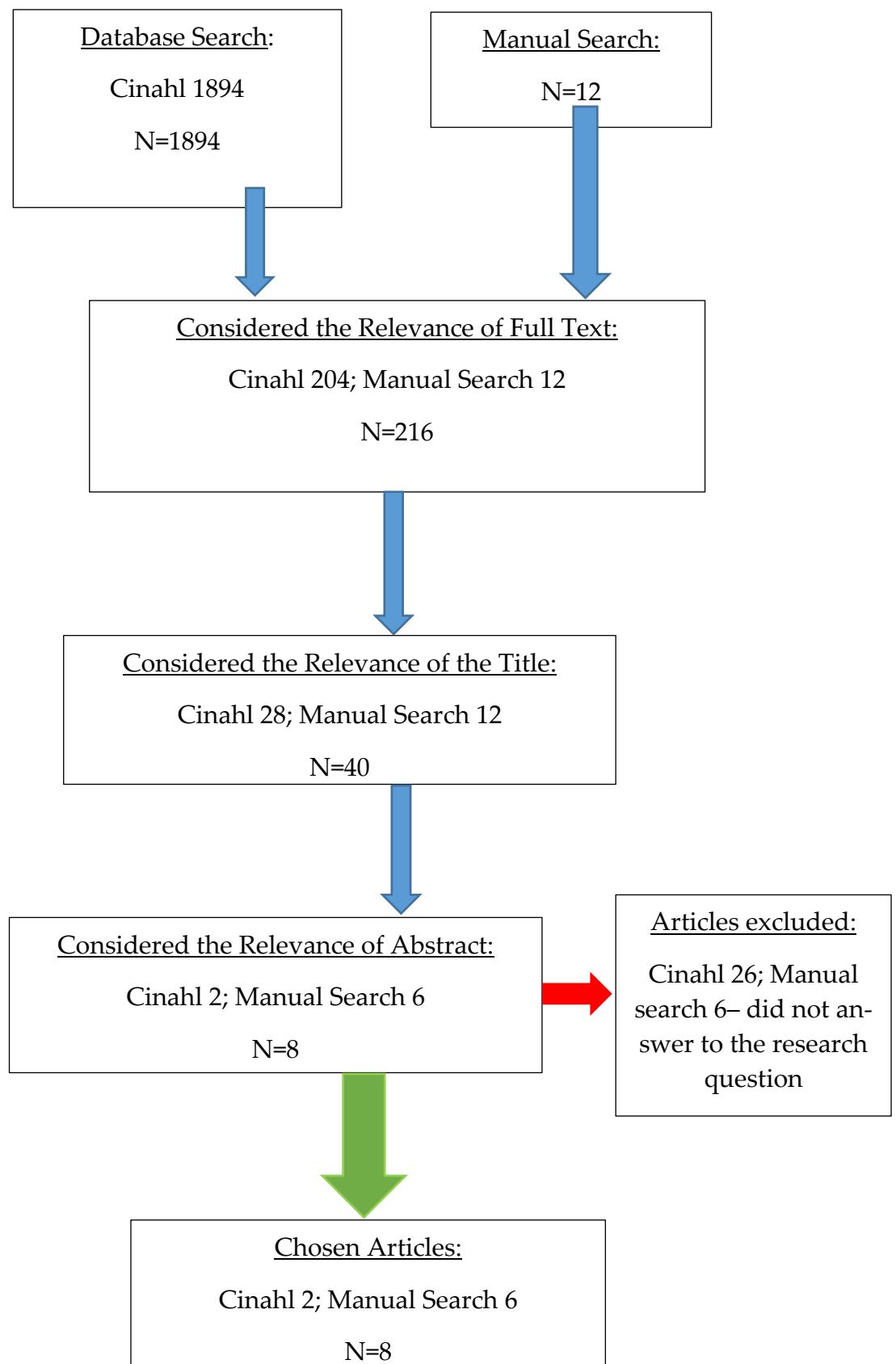


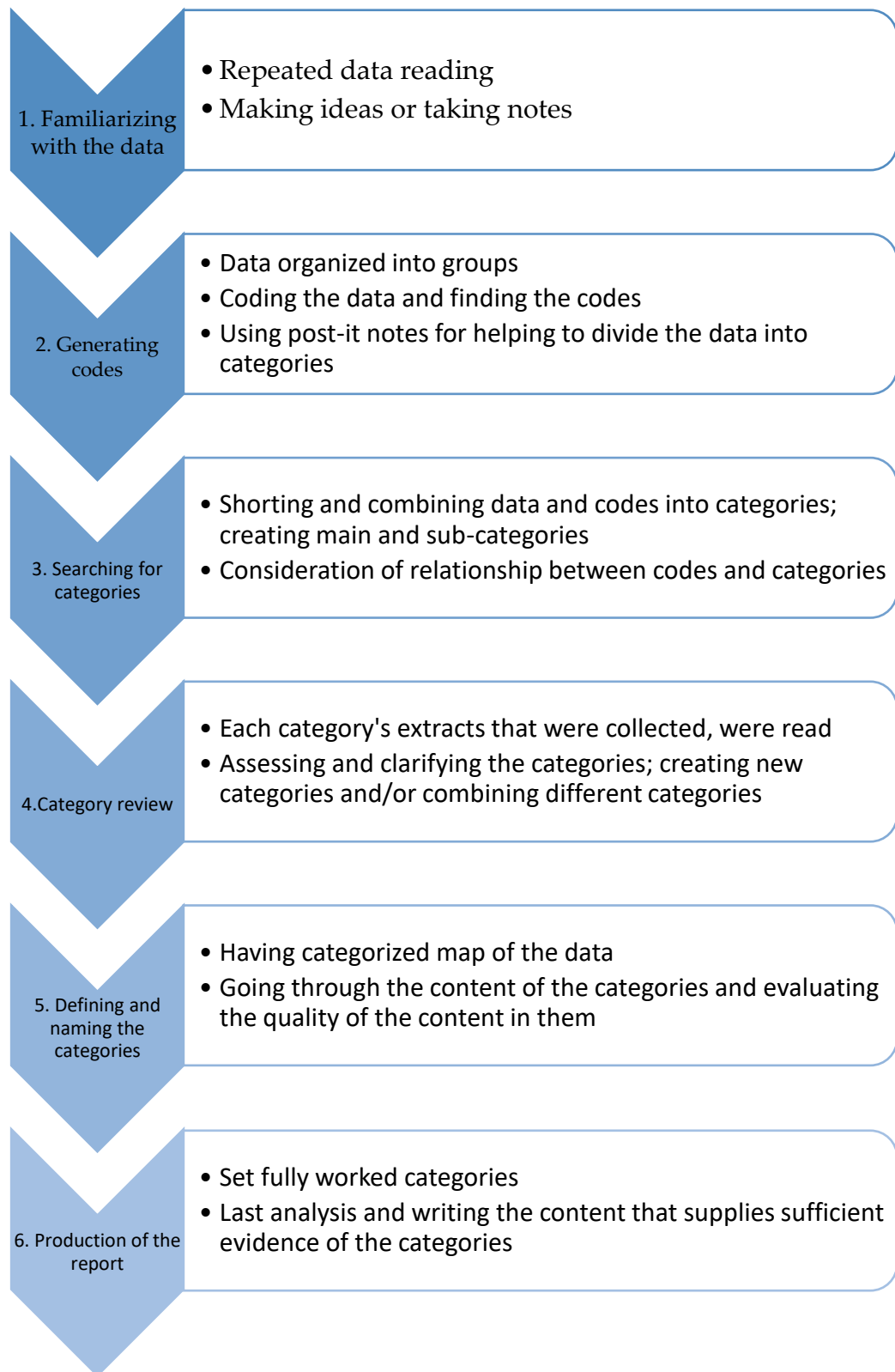
Figure 1. Article Search Process

Data was collected from N=8 sources for the literature review. Article search from the databases was processed by one person only – consideration of the relevance of both titles and abstracts was included. A manual search was accomplished by using the same keywords and topics, this was performed by one person only, which resulted to 6 different sources. First, only topics and abstract were read, suitable articles for the research were completely read through, until the best articles were left and afterwards were included. Selected articles were read through and determined with the criteria that can be seen in Table 1.

### **5.3 Data Analysis and Synthesis**

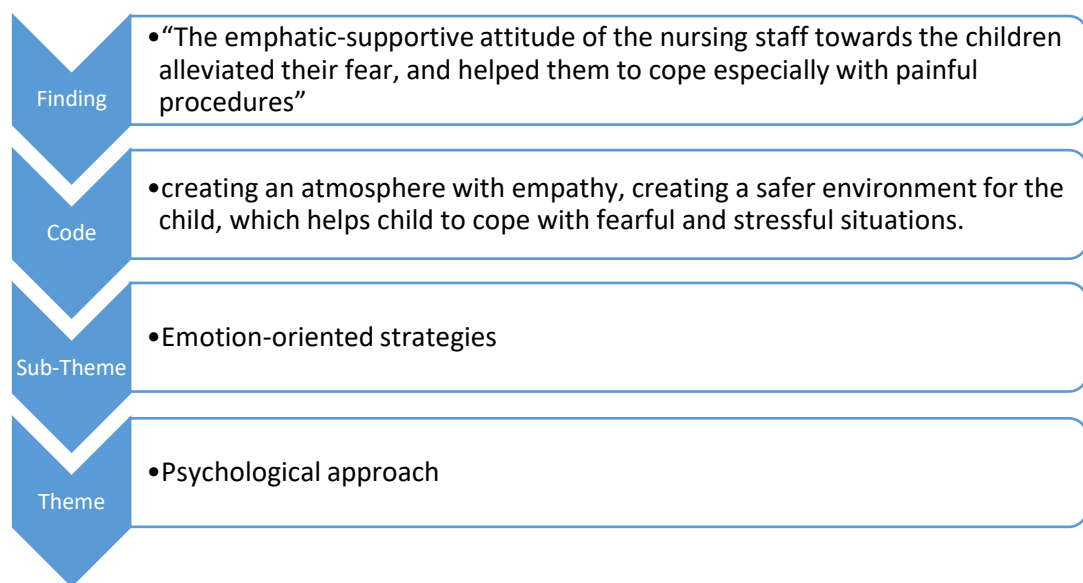
The data that has been used in the thesis has been analysed by collecting information from various scientific sources and research-based articles. Data in this thesis has been selected by using earlier mentioned inclusion-exclusion criteria. Data collection of this thesis is done with content analysis method, which is presented in Figure 2. This is allowing one to make replicable and legitimate conjecture from data to one's context. This allows one to summarize studies in a systematic way including classification (Elo & Kyngäs 2007). The methods used are inductive (its origin is from the data) and deductive (its origin is from theories) (Elo & Kyngäs 2007). This thesis is based on inductive content analysis method. It was chosen to get correct information from the previous researches. For the writer this method was most practical way to carry through

In inductive content analysis the researcher goes through data, finding and creating codes and combining them with other codes, which data has similarities to form sub-categories, -themes and -concepts. Furthermore, to combine them into categories, themes and concepts. (Elo & Kyngäs 2007)



*Figure 2. Six main phases performing inductive content analysis*

The information is being selected by the relevance of the information to the topic. After reading all the articles alone, parts from theoretical, results and discussion parts of the chosen articles were assembled, which answered to the research question and topic. These parts were branched into categories and sub-categories for more specific information associated to the issue. Themes and sub-themes were described and defined. Throughout the analysis process, colour coding had been used in many states of the process. After all the findings from the data had been found the data was decoded and utilized into the thesis document and was made into more clear form of text, which created the Result part of the thesis. Afterwards, the categories and themes were modified several times. Every part of the analysis part of the articles was done alone. Demonstration of data analysis process found in Figure 3.



*Figure 3. Example of data analysis process.*

## 6 Results

Synthesis and Analysis of the material that has been selected to current work produced three main categories of how nurses can help child during blood cancer treatment: Family-Centred Care, Psychological Approach, Medical

Care (Table 2). Themes mentioned before gives overall understanding of the methods that can be used in care.

*Table 2. Metods of How Nurses Can Support Child Categorized into Main Themes and Sub-Themes*

Research Question	Themes	Sub-themes
How nurses can help children with blood-/lymphatic cancer during their treatment	Family-Centred Care	<ul style="list-style-type: none"> <li>○ Maintaining Self-Determination</li> <li>○ Education</li> <li>○ Empowerment</li> <li>○ PTSD care</li> </ul>
	Psychological approach	<ul style="list-style-type: none"> <li>○ Emotion-Oriented strategy</li> <li>○ Cognitive-Oriented strategy</li> </ul>
	Medical care	<ul style="list-style-type: none"> <li>○ Help with pharmacotherapy</li> </ul>

## 6.1 Family-Centred Care

### Maintaining Self-Determination

Not violating children's self-determination rights has been proven to reduce fears and stress during the stay in the hospital, due children feel safer when they have been heard. To redeem trust between the patient and nurses, it is necessary to maintain the self-determination right. (Koistinen et.al 2005) The child deciding what to wear or what to eat is seen as one of the good coping

methods and children have addressed them as important. If self-determination was taken away, children had increased amount of stress. (Salmela 2010, 20,48)

Self-determination of a child, creation of safe environment by addressing their fears and comforting them and handing out knowledge and explaining things that are to be done, are some good ways to relieve stress from the children. Building confidentiality is important and nurses can gain this by addressing the child's fears and responding to their needs. Confidentiality can be enhanced with activities that the nurses do with the children. (Koistinen et.al 2005) The information for patients and their care givers is very much in need. It is necessary to explain the disease and its usual prognosis individually step by step. Creating confidentiality and communication skills with the nurse is needed when explaining daily the program, explaining the side-effects and allowing child patient to be part of the daily program planning. (Koistinen et.al 2005)

### **Education**

Nurses can have a big impact on helping children to manage with the changes and possible symptoms, which occur because of the treatment. The effect of playing and treating a child as a child while the treatment is going on, allowing the child to have emotions and including parents to the care as much as possible, are seen as important factors for children to cope with challenges that the treatment includes. Every child is an individual and should be treated by their needs. (Salmela 2010, 20, 43). Explanation of every procedure is necessary, to be able to support the child better. If information and explanation is not proper enough this can result of stress and anxiety to whole family. (Weißflog et.al. 2016, 1450-1453.)



Family-Centred Care (FCC) is effective and has been a philosophical principal for decades. Helping the parents will help the children. Education provided to parents is important, due it has benefits on children and themselves, and sufficient information provision is to help parents to gain back the feel of control over the situation. Explaining situation to parents gives more steady results in coping and parents can help better. (Krisnana et al. 2019, 1038-1039)

Children are usually most afraid of the nursing intervention; pain being one of the largest reasons for fear, whereas other discomfort being close second.

Nurses, with multi-professional team, should provide a safe environment by including parents to the care and having familiar health care members during the hospital interval, providing information according to the level of their developmental stage, building the confidentiality by doing things that one says, and managing the pain is seen as an important stress relief factor. It is necessary to state that the child should get enough rest as well as they have enough activities that interests them. (Salmela 2010, 20, 43: Weißflog et.al. 2016, 1450-1453.)

### **Empowerment**

Empowerment module Krisnana et al. (2019, 1035-1036) could be used as a method to help the children, by providing support to parents who are able to provide more support to the child. (Krisnana et al. 2019, 1038-1039) Parents are counted as the most important support for the children with stress, because they know their children's behaviour. In the beginning, the nurse should focus on the parents, due to the crisis they are likely having. The emotional rush that parents have affects their psychological health, thus it is important to remember to help parents with emotional coping. Parents should be supported, encouraged to have feelings and allow them to talk about it and be open about it. (Salmela 2010, 20, 43) Nurses should follow the crisis nursing

pathway. (Traumaterapiakeskus 2019) The adverse effects should be addressed by providing or guiding parents to psychological support; thus, it is necessary to pay attention to the parents to reduce possible severe adverse effects (Krisnana et al. 2019, 1038-1039).

At young age, children are reflecting their mood by the facial expressions, children usually mimic parents' mood. If parents are feeling stressed and show it, or they are feeling scared and worried, the child will notice this from their parents' behaviour and might start acting out. (Krisnana et al. 2019, 1038-1039) A child at young age is very observative. They are learning things by reading the reactions of the parents, thus, if parents are feeling anxious or scared and the child can detect this, the child starts to be worried and stressed as well.

### **PTSD Care**

If a nurse encourages the parents and addresses their fears, it is more likely to have steadier results when it comes to the level of stress, and the risk for post-traumatic stress disorder (PTSD) is reduced. (Koistinen et.al 2005) PTSD is common with children who have had cancer. By focusing on the parents in the early state of the cancer diagnosis nurses can prevent possible PTSD.

When parents can support the child, they will recover faster and will have a more positive attitude, which effects on the amount of mental health problems in the later stage. Posttraumatic situations can be used as a method to grow, meaning, when a person faces a posttraumatic situation, with positive experiences the negative ones can be used to grow in handling the posttraumatic situations and other stressful moments in life (Hong, Park & Choi, 2019, 9-11, 15).

## 6.2 Psychological Approach

### Emotion-Oriented Strategies

As important as a care giver and the nurses are, the parents of the child have an important role in supporting the child by creating a safe environment.

Emotion-oriented strategies in coping (Salmela 2010, 17) require the nurses to help the parents, so they can function. Together parents and nurses can provide a safe environment where nurses can gain confidentiality in the sight of the child. (Krisnana et al. 2019)

In emotion-oriented strategies of nursing (Salmela 2010, 17), the nurses who are part of the activities, allow parents to be part of the procedures and activities, and encourage the child during procedures, can gain a better bond and trust with the patient. It is important for the whole family and nursing staff, who are taking care of the child, creating an atmosphere with empathy, creating a safer environment for the child, which helps child to cope with fearful and stressful situations. (Salmela 2010, 17-18).

Nurses following evidence-based guidelines and implementing them in practice, calm and secure actions while doing procedures, helps children to calm down. (Koistinen et.al 2005) Koistinen et.al. 2005 says that it is important to have enough activities and things to do, but it is as important to secure a calm environment for the child to be able to help the child to cope with stressful and scary situations.

Children have been reported to be most afraid of the nursing interventions while being in the hospital. The idea of being a patient and having an unfamiliar environment has raised the fear level of children in age 6. (Wennström & Bergh 2008, 65-76.) During cancer treatment there are plenty of things happening and the environment can feel strange and scary. Fear of separation has been reported to be one of the biggest fears with children, among the pain

which comes from nursing interventions. Regardless to the treatment or disease, it has been reported that children feel less afraid outside of hospital than while their stay in the hospital. (Salmela 2010, 11-15)

When it comes to the time of treatment, the child can feel stressed beforehand, because they know the outcome of feelings that comes after the treatment such as pain and nausea. During the treatment, it is important to have confidentiality with the child by being honest, taking care of discomfort and explaining what is happening, according to the developmental stage, working as a team with the nursing team, parents and child, and creating a safe environment by including parents by allowing them to be next to the patient and creating a calm environment. (Weißflog et.al. 2016, 1450-1453.)

Depression and anxiety in children are usually present when the treatment of blood cancer/or lymphatic cancer is currently running, and the nurses should provide emotional support for the child among with parents. (Koistinen et.al 2005)

### **Cognitive-Oriented Strategy**

It has been reported to have a good impact on the child's coping process when the nurse discusses the experiences with the child (Salmela 2010, 17-18). The nurse can implement the cognitive-behavioural package or cognitive-oriented strategies of coping, which include obtaining information and allowing the child to be a part of decision making, which can help the child to manage the fears before treatment or any type of intervention (Lindberg & von Post, 2006, 143).

Including children to the activities, giving special attention and being in interaction with other children on the ward if possible, for those who have intensive chemotherapy, parents and nurses have a big role of taking patient's mind off by providing activities and rest. By participating to the activities

with the child, parents and nurses can have a good impact on the mood of the child, which promotes the child's mental health and reduces the stress levels. These helps children to forget the pain and the nausea feeling that they may have, these can reduce the stress levels of a child while the coping is being increased. (Salmela 2010, 17-18) It is important to create a safe environment where the child and the parents feels safe. Playing games and allowing them to be children is important, but it is important to include the parents to be part of the care. Giving activities for the children takes their mind off from the pain and bad feeling. (Krisnana et al. 2019).

### **6.3 Medical Care**

#### **Help with Pharmacotherapy**

Pharmacotherapy is important to the coping of the child. Treating the side-effects that a child has after the treatment can promote the coping of the child and reduce the levels of stress. Sufficient pain management and management of nausea are important due children have felt that nursing interventions are the scariest, because of the pain and discomfort occurs, (Salmela 2010, 16-17), hence, sufficient pharmacotherapy is necessary to secure the lower levels of stress and anxiety, (Koistinen et.al 2005).

## **7 Discussion**

### **7.1 Ethical Discussion**

To the planning phase of the thesis was spent plenty of time and with great interest to the topic. The way that the thesis was constructed, and the type of the thesis was well matched with the topic, which brought the wide perspective and diversity to the work. The writer's aim was to do honestly and carefully

from the introduction to the discussion. With the wide explanation of the conclusion, the writer aimed to create reliability, and with the careful planning, to increase the validity and ethicality. According to writer there is always possibility in misunderstanding due to the language difference.

Ethical principles have a ground in part of research, instruction situations and development. The aims are to guarantee and foresee a common awareness of the principles and strategic intent (Ethical principle for JAMK University of applied sciences, 2013). The researcher follows the principles of the ethics of the research, to avoid and minimize the risk for plagiarism, fabrication and falsification; meaning, the researcher has put his own effort and represents it and is not offering the works of others as his own. This literature review will be submitted through plagiarism detector system called Urkund system, which is being used at Jyväskylä University of Applied Sciences. (JAMK University of Applied Sciences 2014.)

In this literature review, by using the methods of conduction that was claimed to be used in this thesis. Integrity was held by keeping all the text that was not written by research team have been accordingly referenced, meaning giving the credit to original authors. All the data that has been used for this thesis must be current and have evidence-based background. (Hyvä tieteellinen käytäntö 2013, 28-34)

Throughout the research the aim of ethical norms were trustworthiness, carefulness, objectivity and legality. In order to promote the trustworthiness and elimination of mistakes, ethical consideration in literature review is stated to have no toleration toward any formation of misinterpretation, falsification and fabrication (Hyvä tieteellinen käytäntö 2013, 28-34). Furthermore, reaching ethically tolerable and reliable research results in current work, interpretation,

application and assessment of ethical rules, the responsibility of the conduction is by authors (Hyvä tieteellinen käytäntö 2013, 6-10; Tuomi & Sarajärvi 2018, 120-125; Niela-Vilén & Hamari 2016, 31-33).

## **7.2 Reliability and Falsification**

Falsification, meaning misrepresentation of the information that is leaving out information and intentionally manipulating information. Principles according to the Hyvä tieteellinen käytäntö (2013) will be followed so falsification will be avoided.

To the reliability of the research article/articles from organizational pages if it has been done with good ethical principles. By them it is secured reliability and ethically based acceptance. (Hyvä tieteellinen käytäntö 2013, 6-10.) Along the ethical principles the reliability- and assessment criteria are needed to secure the ethical endurance of the thesis. Along the previously mentioned criteria, to the quality of thesis affects other good quality principles and the pressure and settings of an individual. (Tuomi & Sarajärvi 2018, 120-125.) As an important factor of the reliability of this thesis is that it can be repeated easily, and following the steps of literature review, the repeatability should be good in this work (Niela-Vilén & Hamari 2016, 31-33). According to the writer there is possibility in misinformation in the case writer has understood the material incorrectly.

During every stage of the progress of the thesis there was constructive feedback from the mentoring teachers, in order to promote researches' publication, and moulding the results of the research easy to understand and easy to read for the mass readers.

## **Limitations**

Despite the difficult- and restricted access to the material along with the focused area of a child patient with hematologic cancer and the lack of research

in the area, the research questions of the thesis were answered. As the thesis was in its final stages, the writer realized the lack in the specification in the nursing interventions to the cancer treatments. The search of the articles was limited to the databases that Jyväskylä University of Applied Sciences provide. In some articles the sampling scale was minor, thus, reliability of this thesis is questionable.

In the text, mistakes might occur on the interpretation of the text, due the mother tongue of the writer is not the language the text is written in. The interests of the writer might affect the focused area in the thesis. Despite the writer is satisfied with the work, these factors are reducing the validity of the thesis.

## 7.3 Discussion of Results

### Analysis

The aims of the thesis were to provide information on how a nurse can help a child during the blood/lymphatic cancer treatment and how cancer treatment can have an effect on a child's emotions, mental health, development and how it affects the parents. There were many international studies done before on the topic of the thesis(N=8). Researches were wide, but consisted reliable research methods for data, sources and findings.

The thesis was done as an individual performance, which affected on the usage of time, hence to the scope of the material. The chosen researches are either in English or in Finnish. To the language of the article affects the access to the full article and the reliability of the article. Due to the translation there might be mistakes that are open to interpretation. The information explained in the *results* part of the thesis was similar as expected.

There is need for different amounts of support and nurses can provide psychological support, promotion of coping with distractions and management of



the pain, depending of the background of the child patient. Building the trust, and confidentiality between the nurse and the child patient is one of the corner stones of the supporting care. (Salmela 2010, 11-15) These ways of support were considered much better than no support, or support which would have been limited either to the child or to the parents (Koistinen et.al 2005).

Emotion-Oriented strategy have good impact to the coping of the child (Salmela 2010, 11-15). There are many possible things that might affect the child (Krawczuk-Rybak, Panasiuk et.al. 2018, 440-442), but with emotion-oriented strategy these side-effects were not so severe (Salmela 2010, 11-15). This shows the importance of the emotional support that is given to the child which mostly is given by parents (Reisi-Dehkordi et.al. 2014, 334).

Pharmacotherapy has a big role in coping. Nurses' ability to make it game like experience can help the child to cope better with the fear and changes (Salmela 2010, 17-18) It is undeniable that sufficient pharmacotherapy is necessary to have. Assisting to cope with pharmacotherapy and with different coping strategies (Salmela 2010, 16-18), it seemed to be important to keep the trust between care staff and the patient. Findings shows that self-determination has shown to have good impact to the care and reduces the anxiety and stress of the child. Self-determination has big role in producing the bond to care and to the care staff. (Koistinen et.at 2005)

FCC is the most used supporting the child during the treatment (Krisnana et al. 2019, 1038-1039). Most of the findings links somewhat to the FCC showing that inclusion of the family to the care and maintaining the rights of the patient, which has been proven to be beneficial to the patient in long term care plan (Krisnana et al. 2019, 1038-1039; Salmela 2010, 20, 43)

Due to the studies N=8 have been done in different parts of the world there is higher prove that these found methods can be applied in most part of the

world, the limitation for using these is the possibility of family being part of the care, but in any means these should and could be done in all parts of the world to promote the support that is given to the child.

## **7.4 Conclusion**

The aims of these studies are to provide general understanding on what children go through while cancer treatment, and what/how we as nurses can do to support children to manage through a treatment program. Challenges that nurses might face during the treatment and the importance of the family throughout the treatment. Importance of the everyday activities, and allowing the child to behave like a child, play with toys and colour the colouring books. Physical and mental challenges that children might face due to the treatments.

Despite, according to the writer, the aims of the thesis were reached, and the research question was answered. It was surprising that the clear answer to the ways to support was not reached. The creation of the feeling of safety, providing activities and self-determination among the inclusion of the parents to the treatment and pain management turned out to be the most used and effective ways of support.

## **Suggestions**

Analysed material, which was used, can be seen that the holistic care and communication skills and authenticity of the nurse are needed to secure good quality care and support. Because there is lack of data from Finland in the area of children's hematologic cancers, further researches are needed and justified by the writer. Nurses who work in the field of paediatrics can benefit from the thesis in further investigation and research.

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## Appendix

Appendix 1. The reviewed articles in alphabetical order

Author(s) Publishing year and country	Title	Purpose	Research method	Main findings
Hong S., Park H. R., Choi S. H. 2019. South-Korea	Posttraumatic Growth of Adolescents with Childhood Leukemia and their Parents	To see the amount of post traumatic growth participants (family and patient) have had	Qualitative research	Nursing intervention programs that involve modifying core beliefs and inducing a positive thought can help adolescents with leukemia and their parents grow after traumatic events.
Koistinen P., Ruuskanen, S & Surakka T. 2005, Finland	Lasten ja nuorten hoitotyön käsikirja	To provide information about and paediatric nursing	Paediatric nursing guidelines	Paediatric nursing guidelines are useful when education to nursing staff and students is needed to be provided.
Krisnana I., Sulistyarini H., Rachmawati P. D., Ariel Y. S., Kurnia I. D. 2019. Indonesia	REDUCING ACUTE STRESS DISORDERS IN MOTHERS OF LEUKEMIC CHILDREN BY MEANS OF THE FAMILY CENTERED EMPOWERMENT MODULE (FACE)	To analyze the effect of a parenting empowerment module, with the aim of reducing the stress experienced by the mothers of children suffering from leukemia	60-person randomized trial research	Cognitive empowerment can improve the understanding of parents caring for leukemic children, and reduces the levels of stress associated with child hospitalization.

Lindberg S. & von Post I. 2006.	From fear to confidence: children with a fear of general anaesthesia and the perioperative dialogue for dental treatment	Describe what may help children to manage their fear of general anaesthesia.	35-child patient Qualitative: research	Continuity of the care inspired confidence in children which helped them to manage fear of General anaesthesia
Salmela M. 2010. Finland	HOSPITAL-RELATED FEARS AND COPING STRATEGIES IN 4-6-YEARS-OLD CHILDREN.	The purpose of the study is to describe the experience of hospital-related fears and the experience of coping with hospital-related fears of 4-6-year-old children.	89-person Qualitative research: semi-structured interview	The results revealed that more than 90 % of the children said they were afraid of at least one thing in hospital. Most of the fears could be categorized as nursing interventions, fears of being a patient, and fears caused by the developmental stage of the child.
Traumaterapiakeskus 2019. Finland	Psykykinen trauma	To provide information and guidelines for crisis nursing	Crisis nursing guidelines	Crisis nursing is important part of nursing care and should be implemented when crisis is present.
Wennström L. & Bergh I. 2008, Sweden	Bodily and verbal expressions of postoperative symptoms in 3- to 6- year-old boys.	The aims of the study was to investigate small boys between 3-6 years of age describe boldly and	Quantitative research: semi-structured interview	Small children have difficulties in distinguishing pain, nausea, and anxiety and that post-operative discomfort was experienced in



		verbal expressions of postoperative symptoms		many different ways.
Weißflog, G., Hönig, K., Gündel, H., Lang, D., Niederwieser, D., Döhner, H., Vogelhuber, M., Mehnert, A., Ernst, J. 2016. Germany	Associations between dyadic coping and supportive care needs: findings from a study with hematologic cancer patients and their partners	The way couples mutually cope with hematologic cancer is likely to influence their levels of supportive care needs (SCN). Therefore, this study evaluated the levels of dyadic coping (DC) and SCN and the concurrent associations between both variables.	330-patient Quantitative research	SCN of patients and partners were lower in the dimensions health system/information and physical problems/daily living in contrast to those of a cancer patients' validation sample